DOCUMENT RESUME

ED 299 769 EC 211 048

AUTHOR Blackman, James A.; And Others
TITLE Screening Children at Risk: The Iowa Experience.
INSTITUTION Iowa Univ., Iowa City. Univ. Hospital School.
SPONS AGENCY Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Office for Maternal and Child Health Services.
PUB DATE 83
GRANT MCJ-193002-01
NOTE 40p.
PUB TYPE Reports - Descriptive (141)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Developmental Disabilities; *Handicap Identification; *Health Services; High Risk Persons; Infants; Intervention; Longitudinal Studies; *Prevention; *State Programs; Young Children
IDENTIFIERS *Early Intervention; *Iowa

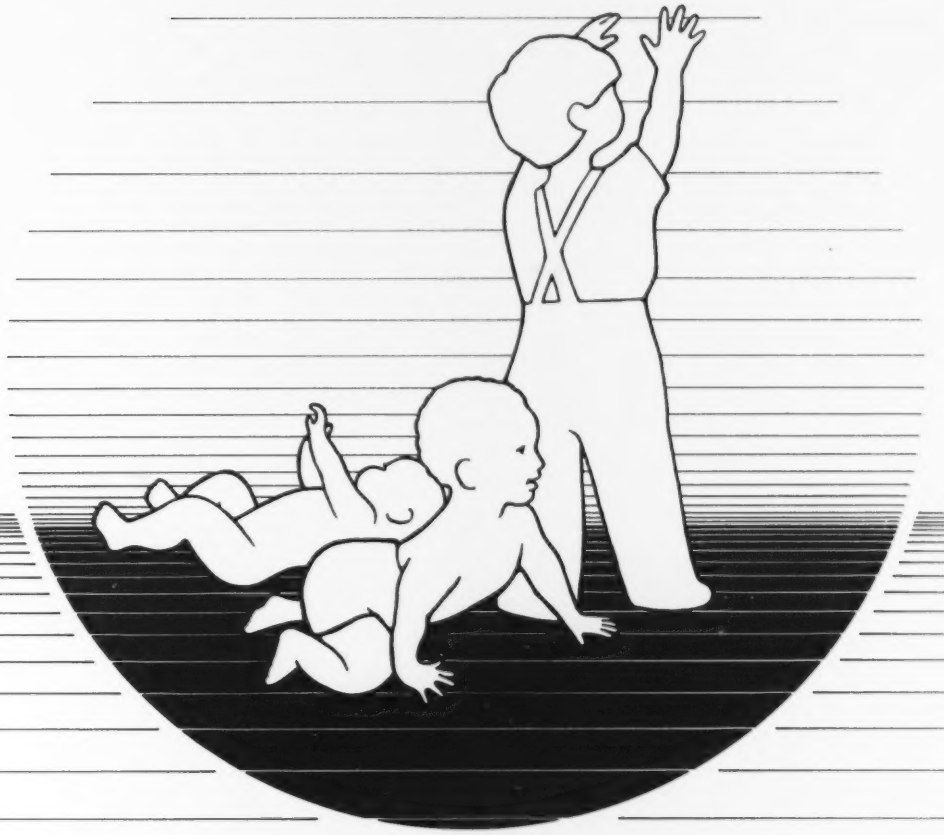
ABSTRACT

The monograph describes the first 5 years' operation of the Iowa Infant Follow-up Program which stresses the early detection and treatment of children at risk for developing disabling conditions. The program has six components: (1) implementing a statewide process for identifying and tracking infants and children at risk for later developmental disorders; (2) determining reliable, valid, and cost-effective methods for identifying such children and their developmental needs; (3) helping primary health care providers coordinate the service referral process for identified children and families; (4) determining training needs and providing training services for personnel serving these children; (5) collecting, storing, analyzing, and interpreting data from the program; and (6) disseminating program results to other states or regional comprehensive child health service systems. Preliminary findings indicate that the program is reaching 80% of eligible children; and that 2,600 referrals have been made. Narrative and statistical data covering demographic information, program funding, eligibility and enrollment, the screening program, referral, perinatal care, and program effectiveness are provided. Stressed is the importance of close working relationships with the state's educational programs. (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

ED299769

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
This document has been reproduced as received from the person or organization originating it.
Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.



Screening Children at Risk:

The Iowa Experience

EC 211048

BEST COPY A

Screening Children at Risk:

The Iowa Experience

James A. Blackman, M.D.
Assistant Professor, Department of Pediatrics
College of Medicine
Staff Pediatrician, Infant and Young Child Clinic
Division of Developmental Disabilities
The University of Iowa Hospitals and Clinics
Clinical Director,
Iowa High-risk Infant Follow-up Program

Herman A. Hein, M.D.
Professor, Department of Pediatrics
College of Medicine
Director,
Iowa Statewide Perinatal Care Program
Director,
Iowa High-risk Infant Follow-up Program

Alfred Healy, M.D.
Professor, Department of Pediatrics
College of Medicine
Professor, Division of Special Education
College of Education
Chairman, Division of Developmental Disabilities
University Hospital School
Director, University Affiliated Facility
The University of Iowa

DIVISION OF
DEVELOPMENTAL
DISABILITIES
UNIVERSITY HOSPITAL SCHOOL
Iowa City, Iowa 52242

DEPARTMENT OF PEDIATRICS
The University of Iowa Hospitals and Clinics
THE IOWA UNIVERSITY AFFILIATED FACILITY

The activity leading to this publication was supported in part by Grant #MCJ-193002-01 U.S. Department of Health and Human Services, U.S. Public Health Service, Health Resources and Services Administration, Bureau of Health Care Delivery and Assistance, Division of Maternal and Child Health.

Foreword

The Iowa High-risk Infant Follow-up Program is based on a recognition of the importance of early detection and treatment of children at risk for developing disabling conditions. Family members are informed through this program about the availability of comprehensive support services and are involved as key personnel in necessary follow-up and follow-through services. The families of infants at risk for disabling conditions often need these sustained and systematic efforts in order to assume their roles as members of the team providing care for their children.

The goal of the Iowa High-risk Infant Follow-up Program was to take the initial steps necessary for identifying the needs of these infants, initiating appropriate referrals, supporting family involvement, and assisting families in negotiating the sometimes intricate paths of the community and state-level service delivery systems. The steps taken toward these goals are described in this monograph, and the program support provided by DMCH reflects its continuing interest in promoting the health and habilitation of infants at risk.

Vince L. Hutchins, M.D., M.P.H.
Director, Division of Maternal and Child Health
U.S. Department of Health and Human Services

Preface

For many years there has been concern that far too many children with handicapping conditions have not been identified at an early age. As a result, many children with physical disabilities or developmental, sensory, communication and behavior problems have not received appropriate intervention services until they are old enough to enter school. One of the reasons why this occurs may be that well-child supervision provided during the first year of life does not routinely include a careful developmental examination, and, after the first year or 18 months of life, the medical care that most children receive is limited to the treatment of acute illness.

One way to address this problem is to have those who provide primary health care include a developmental examination as part of their routines. An additional approach is to conduct public programs, such as the early child-find programs that make developmental examinations available to any child whose parents are concerned about their child's development.

But it is unlikely that these kinds of efforts alone will solve the problem. Therefore, there is an interest in conducting early screening programs targeted toward those populations of infants who are at risk for later manifesting disabling conditions. One population of children who are at great risk are those infants who receive care in modern intensive care units because of low birth weight or other perinatal complications.

This monograph describes one program designed to address this need for early identification of service needs for at risk children and their families. This description is offered, not as the ultimate model in identifying the need for follow-up services, but as one example of a statewide cost-effective approach. It is hoped that this monograph will contribute to ongoing thought and serve as a focus of discussion regarding best practice in these efforts.

Acknowledgments

The authors would like to thank Merle McPherson, M.D., and the staff of the Habilitative Services Branch, Division for Maternal and Child Health, U.S. Department of Health and Human Services, for their reviews and advice. John MacQueen, M.D., director of the Iowa Mobile and Regional Child Health Specialty Clinics at The University of Iowa, also contributed helpful comments.

Special appreciation is due the following individuals for their contributions to this monograph: Janet Healy, data manager; Marilyn Knight, Barbara Smith, and Sandee Wennerberg, editors; Loretta Popp, graphic artist; Kay Rebec, secretary.

We acknowledge the tireless efforts of the pediatric nurse practitioners in the Iowa High-risk Infant Follow-up Program and of Mildred Eggleston, program secretary.

Finally, we wish to express our admiration for the resiliency, strength, and courage of the project children and their parents. We hope that this monograph will encourage efforts to improve and refine support services for them.

Introduction

The importance of comprehensive, coordinated health care services for all children in this nation is widely recognized (Select Panel 1981; AAP 1977; Haggerty 1975) and the lack of such services, especially for children with disabilities, has been well documented (Brewer and Kakalik 1979; U.S. Department of Education 1980).

Comprehensive health care services are of special importance for children at risk for developing disabling conditions. Accumulating evidence shows that the earlier disabilities are detected and treated, the greater the chance for remediation and the greater the chance of lessening their impact on children, families, and society (Simeonsson, Cooper, and Scheiner 1982). Approximately 2 percent of all newborns have discernible disabling conditions. Among school-aged children, this figure rises to approximately 10 percent (Healy 1983). The difference in the incidence figures reflects the fact that various types of disabling conditions become identifiable at different ages. Disabling conditions identified in infancy and early childhood are usually severe health, sensory, and neuromuscular impairments. Disabling conditions identified in the school-aged child are more frequently related to behavioral and educational problems than to physical disabilities.

Clearly, different processes are needed to identify disabling conditions at different stages in the child's development. Iowa has long been a leader in meeting the educational needs of children with disabilities. Special education services were mandated in Iowa for children from birth to 21 before the passage of P.L. 94-142, the Education for All Handicapped Children Act, 1975. However, the public school system does not usually have entrée into the health care system where very young children with disabilities are most apt to be diagnosed and to receive initial services.

In response to a growing awareness of the need for specialized services to meet the health, social, and cognitive needs of children with disabling conditions, Iowa human service agencies developed and implemented a statewide care system to address these concerns (MacQueen 1979; Department of Pediatrics 1979; Hulme and MacQueen 1981). As an integral part of this statewide care system, Iowa agencies responsible for educational, social, and health issues have developed cooperative interagency arrangements to identify and provide health services for children with, or at risk for developing, disabling conditions (Bacon and Healy 1983). A key component of this system is the Iowa High-risk Infant Follow-up Program organized through the cooperation of (1) the Department of Pediatrics (Divisions of Neonatology and Developmental Disabilities) at The University of Iowa; (2) the Iowa Child Health Specialty Clinics, formerly called State Services for Crippled Children (SSCC), Title V; and (3) the Iowa Perinatal Program which is a part of the state's Maternal and Child Health Program.

The Iowa High-risk Infant Follow-up Program

The purpose of the Iowa High-risk Infant Follow-up Program is to identify the developmental and special health needs of infants at developmental risk, to initiate referrals to appropriate agencies if definitive evaluation and remediation are required, to offer support to parents, and to facilitate the family's use of community resources. The program has six components.

1. Implementing a statewide process for identifying and tracking infants and children whose births were associated with specific factors that put them at risk for later manifesting developmental disorders;
2. Determining reliable, valid, and cost-effective methods for identifying such children and their developmental needs as early as possible;
3. Helping the primary health care provider coordinate the service referral process for children and families with identified needs;
4. Determining the training needs and providing educational programs for personnel involved in identifying and caring for such children;
5. Collecting, storing, analyzing, and interpreting the data emanating from the program; and
6. Disseminating the results of these findings to other states or regional comprehensive child health service systems.

This monograph will describe the Iowa High-risk Infant Follow-up Program—its history, current operation, and the preliminary interpretation of results from the first five years of its operation.

Regionalization of Perinatal Care

The National Experience

Recent dramatic changes in the care of sick newborns have supplied growing evidence that sophisticated intensive care practices can reduce neonatal mortality rates (Lee et al. 1980; Kleinman et al. 1978; Horwood et al. 1978; Kitchen et al. 1978). Regionalization, which is the concentration of specific medical services in certain geographic areas, is one way to make these sophisticated practices available to pregnant women and their offspring (Merkatz and Johnson 1976; Hein 1977; Swyer 1970). Regionalization evolved for many reasons. The technology of newborn intensive care was becoming increasingly expensive, and not every hospital could afford the needed equipment. In addition, the medical care of sick and disabled infants (neonatology) was becoming more and more specialized, and sufficient numbers of qualified physicians, nurses, and other support personnel were not available to provide such care. To maintain a high level of expertise in the care of sick newborns, it became necessary to establish facilities capable of providing perinatal intensive care on a regional basis. In order to balance patient needs and available resources, the Committee on Perinatal Health—composed of members of the American Academy of Family Physicians, the American College of Obstetricians and Gynecologists, the American Medical Association, and the American Academy of Pediatrics—developed guidelines for regional networks of perinatal care (Committee on Fetus and Newborn 1977).

A system was developed for classifying levels of care as follows:

Level I hospital centers	provide services for uncomplicated deliveries and normal newborn infants;
Level II hospital centers	provide services for both normal and high-risk pregnant women and for neonates with certain kinds of illnesses. Depending on need and available expertise, Level II centers may approximate either Level I or Level III centers;
Level III hospital centers	function as regional centers and provide all aspects of perinatal care, including intensive care and a broad range of continuously available subspecialty consultation.

The goal of regionalization is to concentrate the care of high-risk perinatal patients in selected centers, yet make that specialized care available within a reasonable distance to those who need it. A systematic attempt to provide care based on such a system has been implemented in many regions of the United States.

The Iowa Plan

Although the focus of this monograph is on the Iowa High-risk Infant Follow-up Program, the prevention or early identification of high-risk status begins during pregnancy. Prenatal care is provided by family physicians as well as obstetricians, but economics affects whether it will be used. Federal support for indigent women needing prenatal care has come from Title XIX programs initiated in 1965. Under the Indigent Patient Care Program, which has served Iowa mothers and children since 1935, women who did not meet the strict eligibility requirements for Title XIX but who still could not afford quality medical care could deliver their infants at The University of Iowa Hospitals and Clinics in Iowa City. Many of these women had high-risk pregnancies, and the program gave them access to both specialized care and free care. The program's prenatal care was provided by University obstetricians at regional clinic sites and by local physicians. More recently, indigent women of low-risk status have been allowed the option of delivering in their home communities, instead of at the University, through the state-funded Medically Needy Program.

The University of Iowa Hospitals and Clinics provides specialized care for the management of women with high-risk pregnancies and of high-risk newborns. However, since wide use of health care is dependent upon its accessibility, it would have been unwise in a rural state like Iowa to consolidate all perinatal services into Iowa's one tertiary care center. Decisions were made, rather, to improve existing services in the local communities, even in hospitals where there were less than 500 deliveries per year. In 1973, an advisory group was formed to start the process of regionalizing perinatal care for women with high-risk pregnancies. Educational programs directed toward those physicians providing obstetrical care were initiated. Pregnant women were screened and those found to be at risk were referred to a center where more sophisticated health care was available. A team composed of obstetrical and neonatal nurses and physicians visited all participating hospitals. Because team members were clinicians and educators rather than inspectors or regulators, the team was well received (Hein 1977). From this effort, three levels of care developed in Iowa.

Medical centers providing all three levels of perinatal care are commonly found in densely populated states. Iowa's rural characteristics appeared to require a system of primary- and intermediate-level facilities with strong referral relationships to a single tertiary-level program.

Level I hospitals include those in more sparsely populated areas. Many counties in the state have only one hospital with maternity services; a few have none at all. Eighty-one percent of these counties have fewer than 500 deliveries a year; 63 percent have fewer than 250.

Level II centers are staffed by obstetricians and pediatricians, generally in private practice, who are boarded in their own specialties but not in such subspecialties as neonatology or maternal-fetal medicine. They do, however, receive ongoing training in perinatal care on a regular basis through the Iowa Perinatal Program.

Iowa has only one Level III—or tertiary—center, located at The University of Iowa

in Iowa City. The Iowa City center also provides Level I and Level II services for the local community. Iowa City is as far as six hours driving time from some areas of the state and some patients are referred to nearby tertiary centers in other states, such as the University of Nebraska in Omaha and the Mayo Clinic in Rochester, Minnesota. Patients referred to the Iowa Level III center include women in preterm labor, women having complicated pregnancies or labor, very small neonates, and newborns with medical problems requiring highly specialized care, such as cardiac catheterization or immediate surgery. The Level II center in Des Moines, which is staffed by neonatologists, functions in some instances as a Level III center.

The Effects of Regionalized Care

Category	Years	#of Hospitals in Category	#of Live Births	% of all Iowa Live Births	#of Births <1,500 gm.	% of Births <1,500 gm.	#of Neonatal Deaths	Neonatal Mortality Rate*
Level I Hospitals (Deliver<500/yr.)	1972	114	18,140	44.0	154	35.0	232	12.8
	1981	106	17,789	38.3	47	13.9	58	3.3
Level I Hospitals (Deliver>500/yr.)	1972	16	11,934	29.0	141	32.1	172	14.4
	1981	12	9,983	21.5	46	13.7	41	4.1
Level II Centers	1972	10	8,982	21.8	116	26.4	131	14.6
	1981	11	15,799	34.1	135	40.1	112	7.1
Level III Center	1972	1	2,153	5.2	29	6.6	31	14.4
	1981	1	2,822	6.1	109	32.3	62	22.0
State Totals	1972	141	41,209	100.0	440	100.1	566	13.7
	1981	130	46,393	100.0	337	100.0	273	5.9

*Per 1,000 live births

H. Hein, unpublished manuscript, 1983.

Table 1. Comparison of mortality rates in Iowa's Level I, II, and III hospitals (1971-1981)

Data resulting from ten years of regionalized perinatal care in Iowa appear to show positive effects from the program. With the exception of the Level III center, table 1 shows a steady decrease in the statewide neonatal mortality rate, especially in the Level I hospitals. The increase in mortality rate at the Level III center reflects the greater number of extremely high-risk patients transferred to that center prior to or after delivery. There was also a significant decline in the number of infants born weighing less than 1,500 grams in all Level I hospitals.

A survey of midwestern states belonging to the Great Plains Perinatal Organization also revealed that those states which had organized, or were in the process of organizing, a regionalized system had lower neonatal mortality rates than those which had not. Therefore, it was concluded that while community hospitals can provide acceptable care to low-risk patients, more sophisticated care is needed for high-risk mothers and their babies (Hein 1980).

The Iowa High-risk Infant Follow-up Program

Organizational Efforts

After a state system to improve pregnancy outcome was in place, the Iowa High-risk Infant Follow-up Program was started in the late 1970s. Since many babies receiving intensive care at birth were at high risk for later manifesting health and neurodevelopmental problems, a series of follow-up evaluations was needed to identify and remediate problems as early as possible. The following organizations were involved in planning such a program:

1. The Departments of Obstetrics and Gynecology and Pediatrics, The University of Iowa
2. The Division of Developmental Disabilities (the Iowa University Affiliated Program), The University of Iowa
3. The Statewide Perinatal Care Program
4. The Child Health Specialty Clinics (formerly State Services for Crippled Children)
5. The Iowa State Department of Health (Maternal and Child Health Division)

Figure 1: Iowa perinatal centers and Iowa High-risk Infant Follow-up Program examination sites

The program started in 1978 with two evaluation sites, one at The University of Iowa, where the administrative headquarters are located, and another at St. Luke's Hospital in Cedar Rapids (see figure 1). To reduce travel time for parents and encourage continued participation in the program, satellite evaluation centers, staffed by personnel from the Iowa City office, were established in Waterloo and Davenport. In 1980, the Level II center in Des Moines, Iowa Methodist Medical Center, the largest locally staffed hospital in Iowa, joined the program. Programs in Sioux City and Ottumwa were added in 1982. In early 1984, additional evaluation programs were initiated in Mason City, Davenport, and Waterloo. One goal of the regional perinatal program was to make follow-up services available close to home for parents and their high-risk children. With the anticipated addition of several more sites, follow-up evaluation services will be available within a reasonable distance to all Iowa children born at high risk. At this time, it is estimated that 80 percent of all Iowa infants whose births are associated with significant biologic risk factors now have follow-up services available to them. Table 2 compares the high-risk infant population from this program to the total Iowa newborn population.

Total births in Iowa:
June 1978-December 1982 214,714
(Average per year 46,847)
(Nonhospital births <1%)

High-risk infant follow-up enrollees:
June 1978-December 1982 1,693

	Total Iowa Newborn Population	High-risk Infant Follow-up Program Enrollees
Mean birth weight	3,440 grams	2,886 grams
Sex		
Male	52%	57%
Female	48%	43%
Maternal age (at birth of infant)	25.0 years	24.9 years
Paternal age (at birth of infant)	27.6 years	27.6 years

	Total Iowa Newborn Population	High-risk Infant Follow-up Program Enrollees
Maternal education		
Grades 1-8	1.9%	2.5%
Grades 9-11	12.6%	14.6%
High school graduate	49.0%	41.2%
Some college	21.7%	27.2%
B.A./B.S.	11.5%	11.9%
Advanced degree	3.3%	2.6%
Paternal education		
Grades 1-8	2.2%	2.6%
Grades 9-11	8.3%	11.9%
High school graduate	47.0%	42.7%
Some college	20.4%	25.5%
B.A./B.S.	13.7%	11.3%
Advanced degree	8.4%	6.3%

Table 2. Iowa newborn profile compared with that of enrollees in the Iowa High-risk Infant Follow-up Program

In an attempt to contain the cost of examinations, pediatric nurse practitioners (PNPs) were recruited and specially trained to provide screening services. Training was provided by the Division of Neonatology and the Division of Developmental Disabilities at The University of Iowa, and the statewide Perinatal Care Program. The nurse practitioners are closely supervised by specialists in developmental disabilities and newborn care. The central program at The University of Iowa is responsible for maintaining the quality of the follow-up services.

Infants who meet certain established biologic (and, on occasion, psychosocial) risk criteria are enrolled in the program while still in the nursery. The screening at 4, 9, 18, and 30 months of age consists of a standardized developmental test and a physical examination administered by a pediatric nurse practitioner. At kindergarten entry and at eight years of age, a more in-depth health and psychoeducational evaluation is performed. Children who fail screening or have other service needs are referred to appropriate community or tertiary resources. The purpose of the program is not to provide direct services, but to identify those infants requiring further developmental evaluation or health care services, and to help families find these services.

Program Funding

Date	Source	Amount	Application
November 1, 1976-March 31, 1978	Maternal and Child Health Division, Iowa State Department of Health	$ 67,000	Salary support. Coordinator and consulting personnel for program development
April 1, 1978-March 31, 1979	Iowa State Services for Crippled Children (now Iowa Mobile and Regional Child Health Specialty Clinics)	60,300	Pilot Program. Total support including salaries for the three pediatric nurse practitioners (PNPs)
April 1, 1979-March 31, 1980	Maternal and Child Health Division, Iowa State Department of Health	100,000	Pilot Program Continuation. Total support
April 1, 1980-March 31, 1984	Robert Wood Johnson Foundation, Princeton, New Jersey	300,000	Program continuation and expansion. Central administration professional salaries $100,000; support salaries $70,000; supplies and services $80,000
February-April 1980-Present	The University of Iowa Hospitals and Clinics, Iowa City, Iowa St. Luke's Hospital, Cedar Rapids, Iowa Iowa Methodist Medical Center, Des Moines, Iowa	contributed	PNP salary support (range $15,000 to $24,000 full-time equivalent per year for each PNP)
October, 1981-Present	Iowa Mobile and Regional Child Health Specialty Clinics	contributed	Shared PNP and support personnel time for implementation of follow-up services in regional clinic sites: Sioux City, Ottumwa, Mason City, Waterloo, Davenport
October 1, 1982-September 30, 1983	Federal Division of Maternal and Child Health	39,456	Salary support. Coordinator, physicians, psychologists for development and piloting of five-year evaluation. Salary support, services for monograph publication
April 1, 1984-June 30, 1984	Iowa Legislature	21,000	Continuation funding
May 1, 1984-Present	Appropriation from Iowa Legislature	50,000	Central program support
July 1, 1984	Iowa Mobile and Regional Child Health Specialty Clinics	33,000	Central program support

Table 3. Iowa High-risk Infant Follow-up Program: Financial base

Table 3 summarizes financial support for the program. The Iowa High-risk Infant Follow-up Program was initiated with support from the Maternal and Child Health Division of the Iowa State Department of Health and by the Child Health Specialty Clinics (Title V). Between April 1980 and April 1984, additional funding was provided by the Robert Wood Johnson Foundation of Princeton, New Jersey. The hospitals which house the regional evaluation sites have provided major financial support through the pediatric nurse practitioners' salaries, the provision of clinic space, and certain record-keeping and administrative costs. The Child Health Specialty Clinics contribute to the program by sharing clinic personnel (pediatric nurse practitioners and secretaries) in Ottumwa, Sioux City, Mason City, Waterloo, and Davenport. Churches and social agencies also support the program by providing examination sites free of cost.

The Iowa High-risk Infant Follow-up Program is now an accepted component of the state's health care system. It provides an important link in the continuum of services to mothers, infants, and the family unit from social, educational, and health care agencies and organizations.

At this time, program services are provided at no cost to the family. This is a critical feature. Many families bear a heavy financial burden from the prolonged hospitalization of their infants. A follow-up program for detecting disabilities may assume a low priority for them. There is no doubt that having the program available free of charge encourages participation. At some point in the future, however, it may be necessary to initiate a sliding fee scale for services, depending on funding resources.

Eligibility Criteria

Infants may be enrolled in the program based on any of the following criteria:

1. A birth weight of less than 1,500 grams
2. Respiratory distress syndrome (RDS) which required mechanical ventilation for two hours or more
3. Other forms of respiratory distress which required mechanical ventilation for two hours or more
4. Documented diagnosis of central nervous system infection
5. Asphyxia neonatorum, as indicated by a five-minute Apgar score of six or less
6. Hypoglycemia, as proven by two consecutive serum glucose levels of 40 mg. percent or less
7. Neonatal seizures
8. Hypotonia at the discharge examination
9. Other (Infants not included in critiera 1 through 8 but who were felt to be at risk by attending physicians. Examples might include newborns who sustained serious intraventricular hemorrhage, infants who show intrauterine growth retardation, or those who will be entering living environments which present severe psychosocial concerns.)

The entry criteria chosen were based on factors generally accepted as related to, but not necessarily predictive of, developmental problems. For the most part, these are biological risk factors. Infants with discernible conditions at birth (e.g., Down syndrome or spina bifida) are not enrolled in this program but are referred immediately for appropriate educational and/or therapeutic services. The ninth criterion allows for inclusion of infants who do not meet any of the eight preceding risk factors at the time of birth, yet are thought to be at risk for other reasons, such as those mentioned.

There is growing evidence that psychosocial factors are possibly more predictive of future development than biological factors. Psychosocial factors interact with biological factors, not only at birth but in the early formative years (Escalona 1982). While these risk factors are very important, there are few valid assessment instruments that could identify them through a screening process. Furthermore, the remedial actions that can or should be taken when psychosocial factors are found to be problematic is open for debate. These psychosocial factors are related to deep-rooted problems in our society. Until a practical means of assessing psychosocial factors that contribute to developmental disorders is available, this program will emphasize the biological factors that affect development and will continue to refer families to appropriate services when psychosocial problems are detected.

Enrollment Protocol

Between June 1978 and December 1982, the parents of 1,693 infants enrolled their children in the Iowa High-risk Infant Follow-up Program. This represents 84 percent of the 2,010 infants eligible for participation in the follow-up program based on the nine entry criteria. Parents of 317 infants (or 16 percent of the 2,010 eligible) declined to take part. The eligible total, 2,010, represents 40 percent of the census in the newborn intensive care units at St. Luke's Hospital in Cedar Rapids, The University of Iowa Hospitals and Clinics in Iowa City, and Iowa Methodist Medical Center in Des Moines during this period.

Figure 2 is a flow chart of the program's services. Infants at risk are identified by the nursery staff. Pediatric nurse practitioners from the follow-up program contact the parents of eligible infants before discharge from the hospital. The purpose of the follow-up program and its operation are explained, as well as the importance of having their children periodically screened for developmental disorders. Infants with severe residual health problems, such as bronchopulmonary dysplasia (BPD), who were patients in The University of Iowa Neonatal Intensive Care Unit (NICU), are followed in a neonatal specialty clinic (staffed by neonatalogists and interdisciplinary teams comprised of therapists, psychologists, and nurses) until they are stable enough to be monitored in the regular follow-up program. Some infants who meet enrollment criteria are identified in the nursery as needing complete assessment and programming. These infants, although few in number, are referred directly to the Division of Developmental Disabilities, or to the Area Education Agencies which provide special education and related services in Iowa.

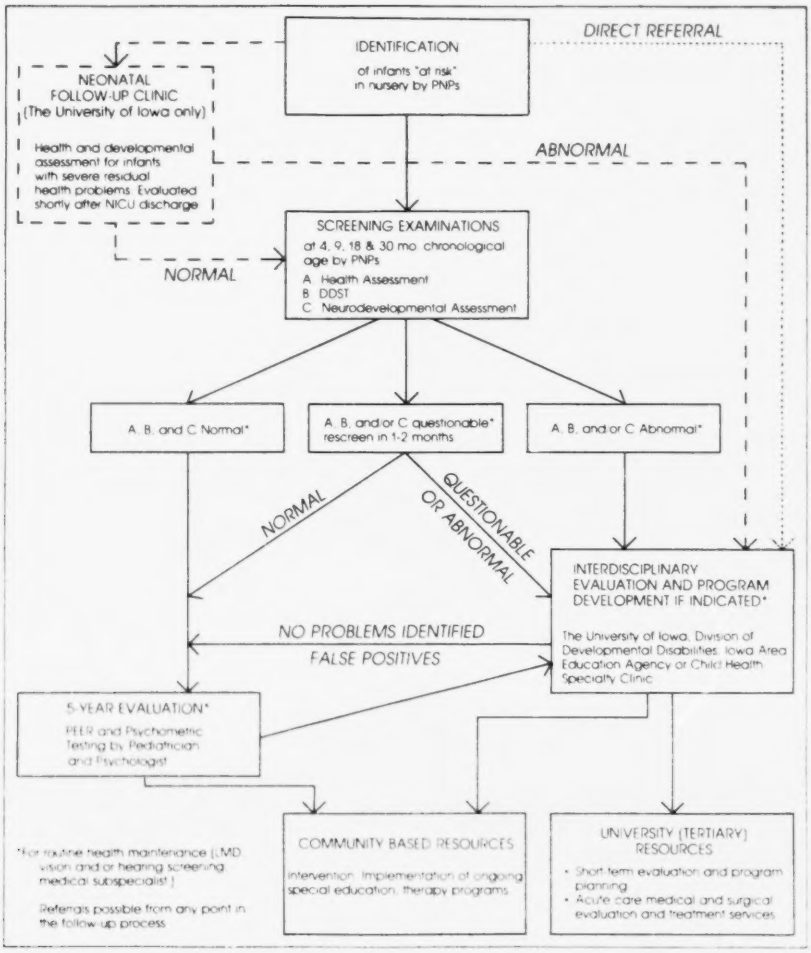

IDENTIFICATION
of infants "at risk"
in nursery by PNPs
DIRECT REFERRAL
NEONATAL
FOLLOW-UP CLINIC
(The University of Iowa only)
Health and developmental assessment for infants with severe residual health problems. Evaluated shortly after NICU discharge
ABNORMAL
NORMAL
SCREENING EXAMINATIONS
at 4, 9, 18 & 30 mo. chronological age by PNPs
A. Health Assessment
B. DDST
C. Neurodevelopmental Assessment
A, B, and C Normal*
A, B, and/or C questionable* rescreen in 1-2 months
A, B, and or C Abnormal*
NORMAL
QUESTIONABLE OR ABNORMAL
INTERDISCIPLINARY EVALUATION AND PROGRAM DEVELOPMENT IF INDICATED*
The University of Iowa, Division of Developmental Disabilities, Iowa Area Education Agency or Child Health Specialty Clinic
NO PROBLEMS IDENTIFIED
FALSE POSITIVES
5-YEAR EVALUATION*
PEER and Psychometric Testing by Pediatrician and Psychologist
COMMUNITY BASED RESOURCES
Intervention: Implementation of ongoing special education, therapy programs
UNIVERSITY (TERTIARY) RESOURCES
• Short-term evaluation and program planning
• Acute care medical and surgical evaluation and treatment services
*For routine health maintenance (LMD, vision and or hearing screening, medical subspecialist)
Referrals possible from any point in the follow-up process

Figure 2: Iowa High-risk Infant Follow-up Program organizational flow

The pediatric nurse practitioners complete an extensive baseline data form on all enrollees from Iowa City, Des Moines, and Cedar Rapids. A short baseline data form is completed for those infants enrolled through Level II centers where time devoted to the program by the PNPs is limited.

Screening Program

The core function of the Iowa High-risk Infant Follow-up Program is the screening process. Developmental considerations, regional needs, and available resources dictated the timing and frequency of the screening, the screening instruments used, and the referral criteria and process. The nine criteria used for determining which infants should be screened have already been listed.

Screening Timing and Frequency

Ideally, screenings should occur no more frequently than is necessary (assuming that the child receives adequate primary care) and at the lowest possible cost. At the same time, they should yield the highest possible return in terms of identifying special health or developmental needs. If visits are scheduled too infrequently, evolving problems may be missed, continuity in health assessments is interrupted, and parents do not identify well with the program. Having visits scheduled too often, on the other hand, taxes the parents' as well as the program's resources, particularly in areas where significant travel time is required. In short, an effective balance must be achieved in the visit schedule. The following age checkpoints were established with these considerations in mind:

Four months.

It is common experience that a developmental exam at four months of age is close enough to the time of discharge to ensure early contact with the parents and early recognition of such problems as muscle tone abnormalities, incomplete immunizations, vision and hearing deficits, or poor growth. However, since many of the infants in the program were born preterm, the actual developmental assessment may be somewhat limited and findings tentative.

Nine months.

Clinical experience suggests that a developmental examination at 9 to 12 months probably provides the greatest opportunity to recognize emerging developmental problems. Significant deficiencies in motor development are usually identifiable at this age, and problems with hearing and vision *must* be discovered by this age (and ideally before) if remediation is to be optimal.

Eighteen months.

By 18 months, problems in language and communication may be more evident, mild motor difficulties are more likely to be detected, and the significantly preterm infant no longer is given an "excuse" for developmental delay.

Thirty months.

At 30 months, language can be assessed more definitively; also, a more accurate screening of cognitive ability is possible through observations of adaptive and social skills.

Five years.

As the child enters kindergarten, it is important to identify more subtle disabling conditions related to learning and behavior, such as poor auditory and visual processing skills or attention deficits. Identification of these problems at this time may lead to early remediation and result in a more satisfactory adjustment to school, preventing secondary problems such as frustration and poor self-image. Only a small portion of the children enrolled in this project have reached five years of age. Data and preliminary interpretations from the five-year-old group are found on page 24 .

Eight years.

Evaluation at eight years involves the testing of capacity and achievement either through direct observation and measurement of the child's developmental abilities or through in-school data collection. Although the eighth year examinations have not yet been accomplished in the Iowa program, it is felt that until a significant amount of carefully collected information is available about a relatively large number of children of this age, we will not be able to answer questions about the outcome of infants born at high risk.

Screening Instruments

Many screening programs, particularly those whose primary purpose is research, rely on extensive standardized assessment instruments such as the Bayley Scales or other specialized tests of developmental and psychosocial function. The use of such instruments, however, is time-consuming and requires a high level of expertise and supervision.

In developing the Iowa High-risk Infant Follow-up Program, there were two important considerations in selecting the appropriate screening instrument: (1) the demands for service within the framework of Iowa's health care system and (2) the importance of documenting the results of the screening process and correlating the results with the initial entry criteria. Because the screening process has proven to be a valid and reliable means of detecting significant developmental problems in infancy (Frankenburg, Goldstein, and Camp 1971; Stangler, Huber, and Routh 1980) and requires less personnel time than in-depth assessment instruments, it was chosen as the appropriate evaluation model for the program. After a review of available instruments, the Denver Developmental Screening Test (DDST) was selected. Training in the use of this instrument was conducted according to the guidelines proposed by its authors. Retraining and review of competency occur on an annual basis.

In addition to the developmental screening test, a physical examination which includes a neurodevelopmental component is performed and the examiner collects information to determine the financial, social, and emotional needs of the child and family.

At the five-year checkpoint, a more elaborate evaluation process occurs since the types of developmental dysfunctions emerging at that age can be more subtle. The methods of evaluating children at age eight have not been determined as yet and will be highly dependent upon program resources. The children enrolled in the program so far have not reached this age.

Personnel

Examinations are performed by pediatric nurse practitioners (PNPs) who are specially trained and supervised by physician specialists in developmental disabilities and newborn care. PNPs were chosen as program service providers for the following reasons:

- They have the skills to evaluate health and physical well-being as well as developmental status.
- They are knowledgeable about child development and behavior and can offer parents guidance about day-to-day care of the child.
- They are specially trained in the coordination of health resources in the community.
- They can reliably perform screening examinations at a lower cost than either physicians or teams involving a health care provider, psychologist, physical therapist and/or other personnel.

Referral Process

Children who have questionable results on the screening test or on the physical examination are retested within six to eight weeks. Children with clearly abnormal developmental or physical examination results or who have questionable results on two successive occasions are referred to an appropriate diagnostic facility for treatment or more extensive evaluation. The screening test is never used to diagnose developmental or neuromuscular problems, nor is it used to identify strengths or weaknesses in individual areas of developmental function such as language or motor development. The child's physician routinely receives a report of the screening results and suggested actions such as immunization update or referral to a specialist. Aware of the stress a high-risk infant may place on the family, the PNPs can suggest family counseling or parent support groups when appropriate.

It is important to emphasize that the follow-up program does not provide direct intervention services; rather, it assists families in obtaining needed services. Whenever possible, referral is channeled through the child's primary health care provider. This professional—usually a family practitioner in Iowa, less frequently a pediatrician, and in some cases a pediatric nurse practitioner supervised by a physician—remains the key figure in managing the child's basic health needs and coordinating the variety of related medical and developmental services needed. The program is not a substitute for the primary health care provider. Specific health services, such as updating immunizations, following up on acute illnesses, and recommending subspecialty referrals, are almost always referred back to the primary health care provider, although the PNPs provide assistance with referrals upon request.

Evolution of the Population	
Total number of NICU admissions in the three enrolling hospitals (The University of Iowa, Iowa Methodist, Cedar Rapids St. Luke's) involved in this reporting—June 1978 through December 1982	4,991
Number of infants treated in the above NICUs meeting criteria for follow-up services June 1978 through December 1982	2,010
Number of infants enrolled in follow-up program	1,693
Number of these infants active through December 1983	1,440
Number of attritions	253
Summary Data on Infants Active in the Program Through December 1983 (N = 1,440)	
Sex	
Male	57%
Female	43%
Birth weight	
<750 grams	1%
751-1,000 grams	4%
1,001-1,499 grams	21%
1,500-2,500 grams	35%
>2,500 grams	39%
Percentage of children born in intensive care-giving hospital	69%
Percentage of children transferred to intensive care-giving hospital	31%
Percentage of children enrolled based on the following program entry criteria (not mutually exclusive)	
Artificial Ventilation ≥ 2 hours	55%
Respiratory Distress Syndrome	43%
Asphyxia	31%
<1,500 grams	27%
Seizures	9%
Hypoglycemia	5%
Hypotonia	3
Central nervous system infection	1
Other (e.g., severe psychosocial concern, intrauterine growth retardation)	11

Table 4. Iowa High-risk Infant Follow-up Program: Population summary

At this time (December 1983), 2,315 infants have been enrolled in this project since its beginning in June 1978. However, presentation of program data would appear to be most meaningful if limited to only those infants who have been in the program long enough to have been through at least two screening examinations. Therefore, only infants born before and enrolled through December 1982 and active in the program as of December 1983 (N = 1440) are included in the discussion section to follow. Table 4 describes this group and summary data on its members.

From the defined population of 1,440, the health and developmental screenings have generated over 2,600 referrals to various health service providers. The term "flagged" was used to identify children needing referrals for developmental evaluation. Referrals based on the health and social needs of both the child and the family were included in the total of 2,600, but children referred for *only* these reasons were not considered flagged.

Table 5 summarizes the various types of referrals generated. There is an average of 1.8 referrals for each child in the program. The majority of the referrals was to the local health care provider for such problems as serous otitis media, incomplete immunizations, poor weight gain, and undefined heart murmurs. Referrals to specialists in the child's local community, such as ophthalmologists, otologists, or orthopedists made up the next highest number. Other referrals include those to the county public health department for visiting nurse services; to the Women, Infants, and Children (WIC) program for food assistance and nutritional guidance; or to the department of human services for social services or for financial or mental health support. The pediatric nurse practitioners serve as facilitators in helping the family understand what services are available and how to access them. Again, these referrals reflect health-related and social concerns as opposed to developmental flagging.

Children who have developmental concerns raised in screening, or flagged children, are directed, with the cooperation of primary health care providers, to one of three major developmental evaluation resources: (1) the University Affiliated Program at The University of Iowa; or (2) regional secondary level health and developmental evaluation clinics staffed by a pediatrician, physical therapist, and audiologist and administered by the Regional Child Health Specialty Clinics program; or (3) one of the 15 Area Education Agencies (AEAs). In any one of these three programs, developmental function is assessed, and parents receive assistance in planning an individualized educational and therapeutic program which makes use of their own community resources. Seventy-five percent of the referrals to the AEAs were for hearing screening only. These were not considered "flagged" referrals. Only 25 percent were for developmental evaluation of flagged children.

	Chronological age when referred					
Referred to:	< 8 mo.	8-15 mo.	16-24 mo.	>24 mo.	Total	Nature of services
Local Physician	67	130	55	33	285	Acute care: Otitis media, upper respiratory infection.
	303	229	175	92	799	Maintenance factors: Immunization update, monitor head growth, monitor cardiac murmur, chronic otitis.
Enrolling Hospital Subspecialty Clinic	119	56	39	46	260	Ophthalmology, orthopedics, audiology, neurology, cardiology, genetics, otolaryngology.
The University of Iowa Division of Developmental Disabilities	53	90	39	6	188	Interdisciplinary education and programming following "failed" DDST and/or abnormal-neurological findings.
Area Education Agency	190	135	75	34	434	Hearing screening (75%) developmental assessment for flagged children (25%).
Public Health Nurse	24	27	19	9	79	Immunization, monitoring and counseling regarding ongoing health, parenting, and nutritional concerns.
Social Services	19	10	1	2	32	Financial resources.
Other Educational Agencies	9	7	1	3	20	Parent-infant centers, Iowa Commission for the Blind, special preschool classrooms.
Other Medical/Social	313	100	63	57	533	Local medical specialists (orthopedists, ophthalmologists, neurologists, physical therapists, nutritionists, urologists, dermatologist); Nonspecialty clinic hospital testing (ultrasound, X-ray); UI College of Dentistry (pedodontics); local dentists, county health departments, immunizations.
Total Number of Referrals = 2,630 = 1.8 referrals/patient						

Table 5. The type and numbers of referrals generated by the program for 1,440 infants

An Iowa law (Senate File 1163) mandates provision of special education and related services for developmentally disabled persons from birth to 21 years of age. Strengthened by P.L. 94-142, Iowa now has a solid statewide network of Area Education Agencies responsible for the provision of special education and related services from birth through age 21 years. The availability of these services around the state is critical to the success of a follow-up program in that even the most sophisticated identification program will be ineffective if appropriate referral sources for remediation do not exist.

RELATIONSHIP OF PERINATAL CARE TO INFANT OUTCOME

The main purpose of this monograph is to describe the Iowa program rather than analyze information gathered from it. Since screening results are not intended to yield definitive outcome data, no attempt is made here to correlate specific biologic or demographic factors with flag rates. Information gathered may be useful, however, in determining trends and needs in perinatal and follow-up services and are, therefore, included here.

Table 4 summarizes data on children enrolled in the Iowa High-risk Infant Follow-up Program who were born between June 1, 1978, and December 31, 1982, and who were active in the program through December 31, 1983. Therefore, all participants presented in this section were eligible, by age, to have received *at least* two screening evaluations.

Of the 2,010 children eligible for enrollment based on the entry criteria, 84 percent (1693) were actually enrolled. The remainder (317) declined follow-up services. The major reasons for declining follow-up were lack of interest in the program or transportation problems. Some parents felt that their local physician could provide adequate follow-up. In other cases, multiple attempts at contacting parents before or after discharge of the infant from the hospital were unsuccessful. Eighty-five percent of those enrolled (1440) participated in screenings at least through the four- and nine-month checkpoints. The overall attrition rate of enrollees, excluding deaths and early referrals made directly from the newborn nursery, was 13 percent. Most of the attritions were families who dropped out of the program between the time of enrollment and the first scheduled screening examination.

Of the 1,440 infants specified, there were 14 percent more males enrolled than females. Twenty-six percent weighed less than 1,500 grams (3.3 pounds) at birth. Thirty-nine percent weighed more than 2,500 grams (5.5 pounds), although many other screening programs only follow infants of very low birth weight. Sixty-nine percent were born at either the University site or at Level II centers in Cedar Rapids or Des Moines. This undoubtedly reflects the effects of regionalization on perinatal care.

The enrollment categories are not mutually exclusive. Therefore, one infant could be included among children receiving artificial ventilation, as well as being among those with respiratory distress syndrome or some other category. Only 26 percent of the enrollees were of very low birth weight (1500 grams). Thus, many children were larger babies (some full term) who had problems such as birth asphyxia or intrauterine growth retardation.

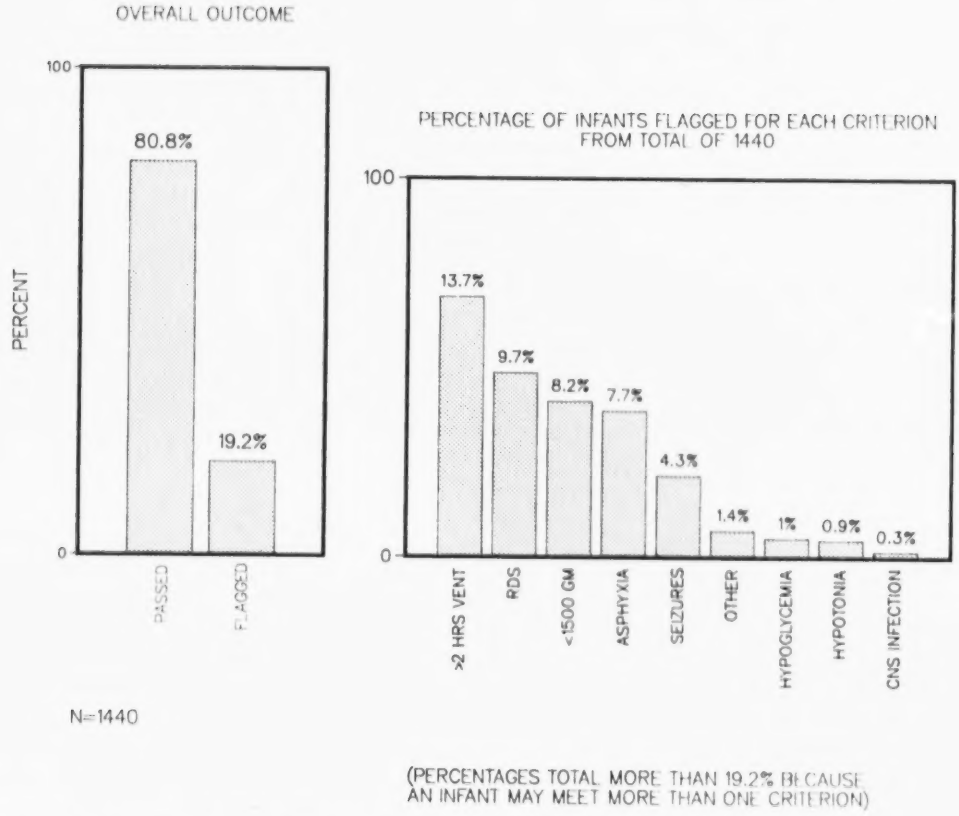


Figure 3: Overall outcome and the effect of each criterion on the percent flagged

Overall infant "flag rate" results are summarized in figure 3. Of the entire population of 1,440, approximately 19 percent, or 277 infants, were designated as "definitely flagged" for further in-depth evaluation based on the screening protocol. Of these, there was a negligible false positive rate. That is, nearly all patients referred for more in-depth evaluation proved to have a significant disability. The false negative rate is addressed on page 24 in a section describing the five-year follow-up protocol.

Figure 3 also shows the percentage of children flagged for each criterion from the total of 1,440. Since the criteria are not mutually exclusive, the total exceeds 19 percent of 1,440.

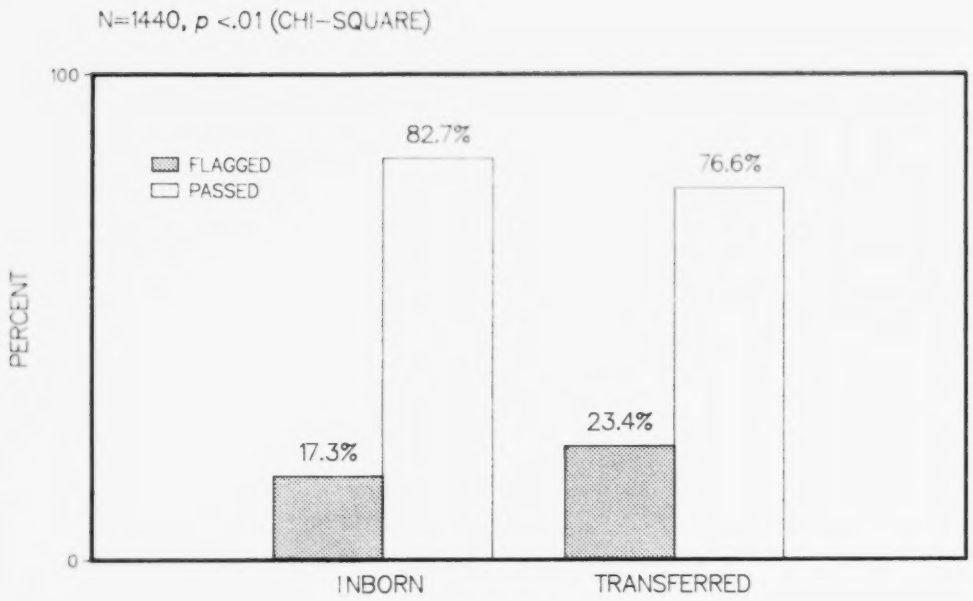


Figure 4: Comparison of flag rate for inborn versus transferred infants

The flag rate for infants born at the intensive-care-giving hospitals was significantly lower than that for infants transferred to these centers (figure 4). However, the relationship between this higher rate of morbidity among infants transferred and other perinatal care factors has not been analyzed and awaits further investigation. The recent moves toward regionalization and a highly organized transport system, including the use of fixed-wing aircraft and jet-powered helicopters, are now allowing Iowa infants to arrive at the neonatal intensive care centers in a more stable condition than before.

Flag rates of males (12 percent) and females (10 percent) were not significantly different.

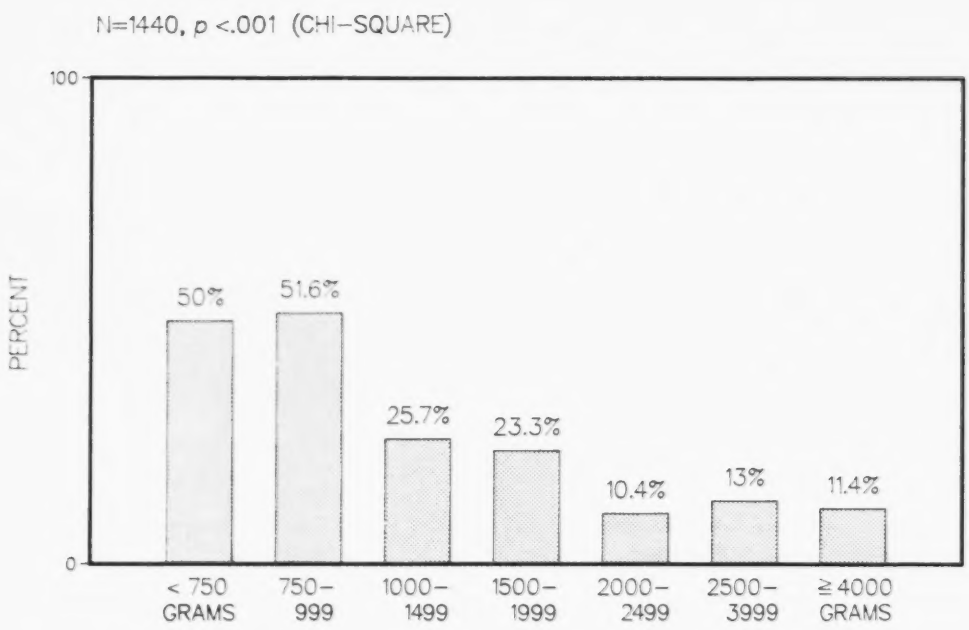


Figure 5: Flag rate by birth weight

The effect of birth weight on outcome is shown in figure 5. Each bar depicts the percent of infants in each weight category who were later flagged for developmental evaluation. The highest flag rate was for infants between 750 and 1,000 grams. The flag rate declines dramatically at 2,000 grams, with a slight rise for infants with birth weights greater than 2,500 grams. The chi-square significance of flag rates for all the weight categories was 89.2, ($p<.001$).

Criterion	Number of Infants Meeting Criterion	Number of Infants Who Met Criterion Who Were Flagged	Percentage of Infants Who Met Criterion Who Were Flagged
>2 Hours on Vent	786	196	24.9
RDS	610	139	22.8
Asphyxia	443	110	24.8
<1,500 Grams	385	118	30.6
Other	162	20	12.3
Seizures	133	62	46.6
Hypoglycemia	77	15	19.5
Hypotonia	40	13	32.5
CNS Infection	16	5	31.3

The total number of infants exceeds the population of 1,440 infants since the enrollment criteria are not mutually exclusive.

Table 6. Infants flagged for further evaluation in each enrollment category

Table 6 indicates the percentage of children within each enrollment category who were subsequently flagged. For example, of 385 children weighing less than 1,500 grams, 118 (30.6%) were identified as needing further developmental evaluations.

Significantly higher flag rates were found in children who met, as opposed to those who did not meet, the following enrollment criteria: respiratory distress syndrome (RDS) ($X^2 = 7.9$, $p < .01$); ventilatory support greater than or equal to two hours ($X^2 = 34.6$, $p < .001$); asphyxia neonatorum ($X^2 = 12.7$, $p < .001$); birth weight less than 1,500 grams ($X^2 = 43.1$, $p < .001$); seizures ($X^2 = 69.0$, $p < .001$); hypotonia ($X^2 = 3.9$, $p < .05$); and other ($X^2 = 5.2$, $p < .05$).

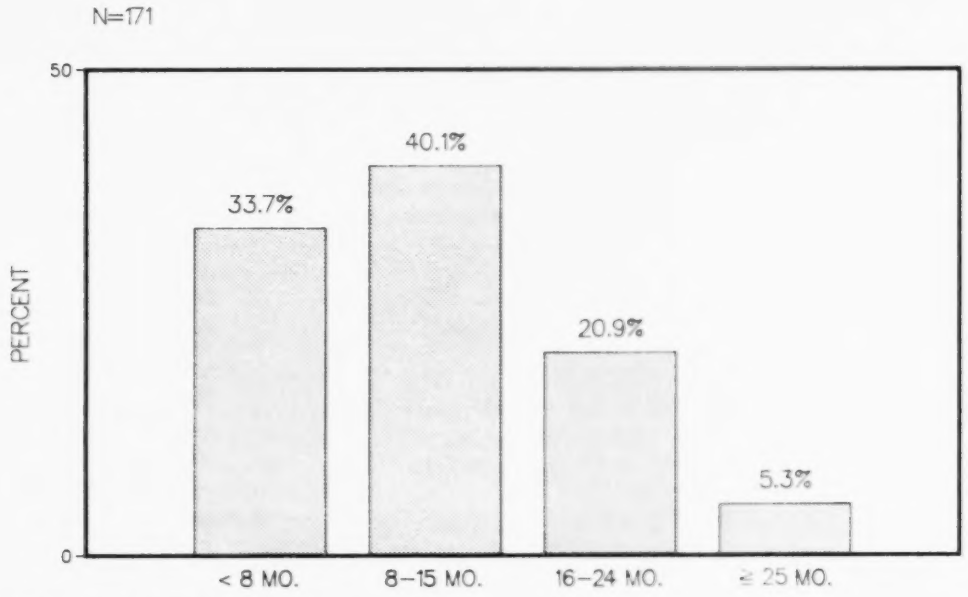


Figure 6: Age at which children were flagged

Figure 6 shows the age intervals at which children were flagged because of failure on the developmental screening or because of a suspicious neurological finding on the physical examination. Results of the five years' evaluation (described later) are not included here since its purpose and protocol are different. Nearly 75 percent of "flagged" children were identified by 15 months of age. The peak flag rate occurred between 8 and 15 months; the cluster period occurred at the 9-month checkpoint.

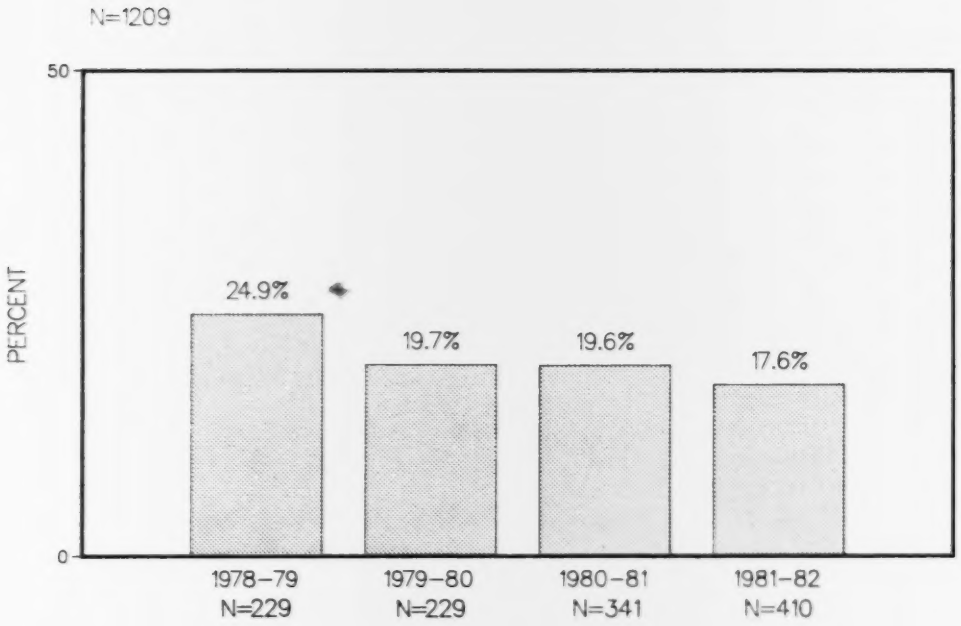


Figure 7: Year-by-year comparison of flag rates

It was noted earlier that the decline in the neonatal mortality rate in Iowa in the last ten years coincides with the inception of the Regional Perinatal Program. The fact that 80 percent of eligible infants in the state have access to the Iowa High-risk Infant Follow-up Program, which utilizes a consistent follow-up protocol, permits some year-by-year comparisons of perinatal morbidity rates. Presumably these rates have some relationship to the regionalization system as well as to improved techniques in neonatal intensive care. While the percentages of children in each enrollment category have remained approximately the same since 1979 (except percentages with birth weight less than 1,500 grams and ventilatory assistance, both of which actually increased), there has been a steady decrease in the flag rate (see figure 7). The difference in flag rates between the first full year of the program's operation (June 1978 through May 1979) and the most recent equivalent time period (June 1981 through May 1982) is statistically significant ($X^2 = 4.5, p < .05$).

In summary

- Eighty-four percent of eligible infants from the three original participating hospitals were enrolled in the program; 85 percent of these were active in the program at least through the first year.
- Nineteen percent of the infants enrolled in the program were flagged for further developmental evaluation.
- The greatest biologic factors associated with developmental risk were very low birth weight, seizures, and hypotonia, although all entry criteria, except hypoglycemia and CNS infection, were associated with statistically significant flag rates.
- Over 2,600 referrals for developmental and health concerns were generated during the first five-year period.
- Delivery of perinatal care appears to be improving most likely due to advances in technology and increased emphasis on regionalization of health care services.

Notwithstanding the promising results of this program, there are questions yet to be answered concerning the concept and methods of screening for this population of children. Primary concern is whether screening is an effective way to monitor high-risk infants. While the research indicates that the Denver Developmental Screening Test is a valid, reliable screening tool, we recognize that a screening tool is not a definitive evaluation instrument; it simply points out the need for further evaluation. However, it is important to note that almost all children who were flagged for further evaluation proved to have a significant disability. The false negative rate will not be known until the tests for definitive health, developmental, and psychosocial problems have been thoroughly analyzed for children enrolled in the program through age five and, if resources permit, through age eight. Therefore, it has been necessary to develop a different kind of program to evaluate these children when they are older.

Program Effectiveness— Evaluation Results of Children at 5 Years of Age Enrolled from Birth

Ninety-five of the children enrolled in the program at birth since 1978 were eligible for the five-year evaluation in 1983. Twenty of these, however, had already been flagged and referred for further evaluation in previous screenings. One of these was a false positive; no developmental abnormality had been identified. Another was diagnosed as having a mild developmental delay and was involved in an Area Education Agency infant program until those services were no longer indicated. Table 7 summarizes information on the 20 flagged children showing why the referrals were made, what action was taken in the referral process, and what problems were subsequently identified.

Over half of the 20 children had been flagged based on results from the DDST only; the others solely on the basis of, or in combination with, abnormal neurological findings. One child was lost to follow-up after the referral recommendation was made. Among the children fully evaluated in the referral setting, problems were identified in all areas of functioning, the greatest number being in the central processing area. Further investigations revealed that of the 14 children diagnosed as having significant problems, 9 were still being followed periodically by the referral agency. Only 2 were known to be enrolled in regular kindergarten at the appropriate age. Eight were in preschool or special education programs. Education programs were not identified for 4 infants.

Agency to Which Referral Was Made:	
Division of Developmental Disabilities, The University of Iowa Hospitals and Clinics	16
Area Education Agency	3
(No referral made)	1
Basis for Referral:	
Failed DDST (1 abnormal or 2 questionable results)	12
Neurological findings	1
Combination of DDST results and neurological findings	6
Clinical judgment even though strict referral criteria were not met	1
Response to Referral for Further Evaluation:	
Refused (attrition from the program)	1
Refused (continued in screening program)	2
Evaluated, no abnormality found, returned to screening program (false positive)	1
Evaluated, placed in appropriate program until such was no longer indicated, returned to screening	1
Evaluated, abnormality found	14
Problems Identified through Further Evaluation: (Diagnoses not mutually exclusive)	
Sensory input problems (Conductive hearing loss, visual disability, glaucoma, retrolental fibroplasia)	6
Central processing problems (Developmental delay, mental retardation, verbal delay)	15
Motor output problems (Spastic quadriplegia, spastic diplegia, questionable neuromuscular involvement, hyperkinesis, motor delay, articulation problem—severe)	9
Physiological health problems (Seizure disorder, hydrocephalus, Prader-Willi syndrome)	4

Table 7. Summary information on the 20 infants in the five-year group previously flagged for further evaluation

Of the remaining 75 children eligible by age for the five-year evaluation, 24 were considered attritions at the 30-month checkpoint. Many of these children, although enrolled at birth, had never participated in any evaluations. Thirteen additional children dropped out of the program between the 30-month screening and the five-year testing. Although the importance of the prekindergarten testing was emphasized, some parents may have felt secure in dropping out since their child had passed screenings through two-and-one-half years and appeared to be doing well. In other cases, the interval during which there was no program contact might have fostered a decrease in interest or concern on the part of parents. Phone or mail contact during this time is being considered to reduce the attrition rate after the 30-month screening.

During the summer of 1983, a pilot testing program was conducted with the 38 remaining enrollees in the Iowa High-risk Infant Follow-up Program who were born between June and September 1978 and who were eligible for kindergarten entry in 1983. They had passed all screening examinations to date. The planned purpose of the program's five-year evaluation is to determine answers to the following questions:

- What are the health and educational needs of high-risk children at school entry?
- What is the prevalence of learning and behavior-related problems which may emerge at age five but which have not been previously detected?
- Has the Denver Developmental Screening Test proven to be a valid and reliable instrument for follow-up of high-risk infants? Were there false negatives or false positives?
- Do pediatric nurse practitioners administer the Denver Developmental Screening Test and perform physical examinations reliably?
- What are the correlations between specific perinatal risk factors and patterns of more subtle developmental dysfunction (e.g., learning problems)?
- Can individual health professionals successfully identify significant health and developmental concerns at school age using the Pediatric Examination of Educational Readiness (PEER)?

The 38 children from the Iowa High-risk Infant Follow-up Program and 68 children forming an age-appropriate control group received in-depth health, psychological, and psychosocial assessments. A pediatrician obtained a medical history, performed a standard physical examination, and administered the Pediatric Examination of Educational Readiness (PEER) (Levine and Schneider 1982), a neurodevelopmental examination developed by Dr. Melvin Levine at the Boston Children's Hospital. The use of this instrument for detecting and clarifying developmental problems in preschool-aged children has been reported elsewhere (Levine et al. 1980).

Tests of language, visual-perceptual-motor, conceptual, memory, orientation, and preacademic skills were administered by a psychologist. In addition, parents completed questionnaires regarding their child's development, behavior, and home environment (see appendix D for a complete list of tests and questionnaires).

Preliminary findings from the pilot project suggest that developmental problems

in high-risk children may become evident for the first time at the five-year evaluation, problems that warrant close monitoring, and, in some cases, early remediation to prevent school failure.

	High-Risk Group (N = 38)	Control Group (N = 68)
No Concern	37%	75%
Mild Concern	39%	21%
High Concern	24%	4%

The early screenings (4-30 months) were intended to detect severe impairments in motoric, sensory, communication, and social skills. As the child matures and approaches school age, problems related to cognitive and behavioral dysfunction are likely to emerge and become recognizable only on more specific and refined measures of developmental performance. Because of the small number of children (N = 38) who have been evaluated thus far, valid answers to the questions posed at the beginning of this section must be delayed until a larger number of high-risk children are evaluated in the program. However, a preliminary look at the first group suggests that either previous screening did not successfully identify children with developmental problems (false negatives) or new sets of problems were detected in a group of children who were supposedly developmentally "clean"; that is, the children had previously passed all screening tests through 30 months of age. This will have important implications for the appropriate length of follow-up, what instruments should be used at various ages, and who should take responsibility for long-term follow-up. There may be a selection process whereby those parents who have lingering concerns about their high-risk child elect to remain active in the program for the duration. It is hoped that the factors which place a child at greatest risk for learning problems will be identified so that scarce resources can be most efficiently applied to the at-risk population.

Comparison of Iowa High-risk Follow-up Program to Other Programs

Program	Gallatin Co. High-risk Infant Follow-up Program Bozeman, Montana	Perinatal Follow-Through Program of Southeastern Wisconsin Milwaukee, Wisconsin	Special Care Nursery Follow-up Program Chicago, Illinois	Iowa High-risk Infant Follow-up Program Iowa City, Iowa	High-risk Newborn Follow-up New York, New York
Affiliations	Gallatin Co. Health Department Bozeman Deaconess Hospital Easter Seals Private Physicians	St. Joseph Hospital Milwaukee County Medical Complex Mount Sinai Hospital SE Wisconsin Perinatal Care System	Rush-Presbyterian-St Luke's Medical Center	The University of Iowa Hospitals and Clinics St. Luke's Hospital, Cedar Rapids Iowa Methodist Medical Center, Des Moines Iowa Mobile and Regional Child Health Specialty Clinics	Bellevue Medical Center New York University
Predominant Geographical Area	Rural	Urban Rural	Urban	Rural Urban	Urban
Funding	City-County Taxes	Affiliated Hospitals Wisconsin Department of Public Instruction (M&CH block grant) Curative Rehabilitation Center	Hospital	M&CH Federal Division Robert Wood Johnson Foundation State of Iowa Legislature Affiliated Hospitals	Federal
Cost	No charge	No charge Third party	PT $35 Psych $56	No charge	$7-17
Intensive Care Nursery Capacity	7	87	41	161	24
Entry Criteria	Hobel Scoring System Pre-Intra Partum >20 Neonatal >10 At Risk for Hearing Impairment (JCH Criteria)	BW < 1,500 grams GA < 32 weeks Vent. + < 2,000 grams CPAP + < 1,800 grams Asphyxia Seizures Meningitis Unusual Behavior in Nursery Exchange Transfusions Hypoglycemia Drug Withdrawal PDA Congenital Infection Congenital Anomalies SGA Request of Neonatologist	1,200 grams	<1,500 grams RDS CNS Infection Asphyxia Hypoglycemia Hypotonia Vent. >2 hours Seizures Other	<1,800 grams Hyperbilirubinemia—requiring exchange transfusion RDS Asphyxia Congenital Anomalies

Tests	DDST DASE Milani-Comparetti Audiology	DDST Milani-Comparetti Denver Eye Test Speech Questionnaire Audiometry Physical Exam	Physical Exam Bayley Scales Stanford Binet Inventory of Maternal Stress & Family Resources Ophthalmology (at 1 year) Audiology (at 8 + 24 months)	4-30 months DDST Physical Exam Interview 5 years Psychometric Evaluation Pediatric Examination of Educational Readiness (PEER) Psychosocial Questionnaire Physical Exam 8 years Undetermined	DDST Physical Exam Ophthalmology (3 mo., 6 mo.) Audiology (9 mo.) Gesell Cattell <3 years Wechsler >3 years Vineland Scale of Social Maturity Carey Temperament Scale by Psychologist in clinic or request of neonatologist
Core Personnel	Nurses PHN OB Nurses Audiologist	PNP PT Audiologist (Neonatologist as a consultant)	Neonatologist Psychologist Nurse PT Coordinator	PNP supervised by neonatologist and developmental pediatrician Pediatrician Psychologist Undetermined	Neonatologist Nurse Social Worker
Frequency	Minimum 2 weeks, 3, 6 months, 1,2,3,4,5 years, 6,7 years (phone only), 8 years	4-6 months (corrected age) 15 months (corrected age)	2 weeks, 4, 8, 12, 18, 24 months (corrected age) and yearly thereafter	4, 9, 18, 30 months (chronological age); 5 years, 8 years	0-6 months (every month); 6-18 months (every 3 months); 18 months-3 years (every six months); 3-6 years (every year)

Table 8. A comparison of five high-risk infant follow-up programs

The follow-up program in Iowa was developed to meet the state's unique characteristics. Other high-risk follow-up programs around the country were surveyed to determine variations in approaches. Information gathered from four other programs are summarized in table 8.

These programs represent varied geographical regions, size, purpose, and funding. Given local needs and resources, diversity is highly appropriate. Yet, each program should build upon the results of others and not unnecessarily duplicate studies. Shared knowledge concerning what works and what does not work is likely to yield considerable savings in cost and frustration. The who, what, where, and when of follow-up must be reviewed and discussed, then tailored to local or regional needs.

The U.S. Department of Health and Human Services (Division of Maternal and Child Health), in collaboration with private groups such as the National Center for Clinical Infant Programs, recently has worked to provide forums for communication and collaboration about the needs of high-risk infants and their families. Such efforts undoubtedly will lead to a sense of "best practice" for the delivery of services.

Summary

The Iowa High-risk Infant Follow-up Program, begun in 1978, has been a natural outgrowth of earlier efforts to improve perinatal health care in Iowa. Serving primarily as a screening and referral program for children born with biologic and related risk factors, the program, now in its sixth year, is reaching 80 percent of eligible children, based on the established risk criteria. The program has been gathering important information on the outcomes of children with various risk factors through its long-term follow-up efforts; and a total of 2,600 referrals based on developmental and health concerns have been made during its first five years of effort.

While there are many questions to be asked about the effectiveness of screening methods, about ways to encourage participation in the program, and about the long-term importance of various birth profiles, the program represents an important commitment to insuring the best possible outcomes for Iowa children through the early identification and referral of those with special needs.

As to the future, there is a need for the Iowa High-risk Infant Follow-up Program, based in the health care system, to foster close working relationships with the state's educational programs, particularly when medically fragile children are involved. Another concern for the future is that the program has been largely limited to infants at biologic risk. For all the complications of these biologic risk factors, it is the psychosocial and environmental risk factors that may present the most complex questions for professionals. What level of environmental risk is not acceptable? How effectively can this be determined? What resources are available to meet needs when such risks are identified? Research strongly suggests that psychosocial factors strongly influence developmental outcomes and mental health, yet as a society we have not decided how to approach these nonmedical risks. Learning more about the relationship between biologic and psychosocial risk factors, through follow-up programs such as ours, will help direct such societal decisions.

References

AAP Task Force on P.L. 93-641. (1977). ***A handbook on child health planning for AAP chapters.*** Evanston, Illinois: American Academy of Pediatrics.

Bacon, R., & Healy, A. (Eds.). (1983). ***Iowa directory of services for persons with developmental disabilities*** (3rd ed.). Iowa City, Iowa: The University of Iowa.

Brewer, G. D., & Kakalik, J. S. (1979). ***Handicapped children: Strategies for improving services.*** New York: McGraw-Hill.

Committee on Fetus and Newborn. (1977). ***Standards and recommendations for hospital care of newborn infants*** (6th ed.). Evanston, Illinois: American Academy of Pediatrics.

Escalona, S. K. (1982). Babies at double hazard: Early development of infants at biologic and social risk. ***Pediatrics, 70,*** 670-76.

Frankenburg, W. K., Goldstein, A. D., & Camp, B. W. (1971). The revised Denver Developmental Screening Test: Its accuracy as a screening instrument. ***Journal of Pediatrics, 79,*** 988-95.

Haggerty, R. J. (Ed.). (1975). ***Child health and the community.*** New York: John Wiley & Sons.

Healy, A. (1983). ***The needs of children with disabilities: A comprehensive view.*** Iowa City, Iowa: The University of Iowa.

Hein, H. A. (1980). Evaluation of a rural perinatal care system. ***Pediatrics, 66,*** 540-46.

Hein, H. A. (1977). Regionalization of perinatal care in rural areas based on the Iowa experience. ***Seminars in Perinatology, 1,*** 241-54.

Horwood, S. P., Boyle, M. H., Torrance, G. W., & Sinclair, J. C. (1978). Mortality and morbidity of 500- to 1499-gram birth weight infants live-born to residents of a defined geographic region before and after neonatal intensive care. ***Pediatrics, 69,*** 613-20.

Hulme, T., & MacQueen, J. C. (1981). ***The provision of coordinated child health services through specialized child health centers.*** Unpublished monograph, The University of Iowa, Iowa Specialized Child Health Services, Iowa City, Iowa.

Kitchen, W. H., Rickards, A., Ryan, M. M., McGougall, A. B., Billson, F. A., Keir, E. H., & Naylor, F. D. (1979). A longitudinal study of very low-birth-weight infants: 1. Study design and mortality rates. ***Developmental Medicine and Child Neurology, 20,*** 605-18.

Kleinman, J. C., Kovar, M. G., Feldman, J. J., & Young, C. A. (1978). A comparison of 1960 and 1973-74 early neonatal mortality in selected states. ***American Journal of Epidemiology, 108,*** 454-69.

Lee, K. S., Paneth, N., Gartner, L. M., Pearlman, M. A., & Gruss, L. (1980). Neonatal mortality: An analysis of the recent improvement in the United States. ***American Journal of Public Health, 70,*** 15-21.

Levine, M. D. & Schneider, E. A. (1982). ***Pediatric Examination of Educational Readiness.*** Cambridge, Massachusetts: Educators Publishing Service.

Levine, M. D., Oberklaid, F., Ferb, T. E., Hanson, M. A., Palfrey, J. S., & Aufseeser, C. L. (1980). The pediatric examination of educational readiness: Validation of an extended observation procedure. ***Pediatrics, 66,*** 341-49.

MacQueen, J. C. (Ed.) (1979) ***A study of the health of Iowa's children and youth.*** Iowa City, Iowa: American Academy of Pediatrics, Iowa Chapter.

Merkatz, I. R., & Johnson, K. G. (1976). Regionalization of perinatal care for the United States. ***Clinics in Perinatology, 3,*** 271-76.

Select Panel for the Promotion of Child Health. (1981). ***Better health for our children: A na-***

tional strategy (DHHS Publication No. 79-55071). Washington, D.C.: U.S. Government Printing Office.

Simeonsson, R. J., Cooper, D. H., Scheiner, A. P. (1982). A review and analysis of the effectiveness of early intervention programs. ***Pediatrics, 69,*** 635-41.

Stangler, S. R., Huber, C. J., & Routh, D. K. (1980). ***Screening growth and development of preschool children: A guide for test selection.*** New York: McGraw-Hill.

Swyer, P. R. (1970). The regional organisation of special care for the neonate. ***Pediatric Clinics of North America, 17,*** 761-76.

U.S. Department of Education (1980). ***To assure the free appropriate public education of all handicapped children: Second annual report to Congress on the implementation of Public Law 94-142: The education for all Handicapped Children Act.*** Washington, D.C.: Author.

THE UNIVERSITY OF IOWA
FOUNDED 1847